

# House File 412 - Introduced

HOUSE FILE 412

BY WINCKLER

## A BILL FOR

1 An Act relating to expansion of the newborn metabolic screening  
2 to include lysosomal storage disorders.  
3 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

1     Section 1. NEW SECTION.   **136A.5B Newborn metabolic screening**  
2 **— lysosomal storage disorders.**

3     1. The department shall adopt rules pursuant to section  
4 136A.8 to expand the newborn metabolic screening required under  
5 section 136A.5 to include screening for lysosomal storage  
6 disorders, including but not limited to all of the following:

- 7     *a.* Krabbe disease.
- 8     *b.* Pompe disease.
- 9     *c.* Gaucher disease.
- 10    *d.* Niemann-Pick disease.
- 11    *e.* Fabry disease.

12    2. An attending health care provider shall ensure that  
13 every newborn under the provider's care receives the newborn  
14 screening that includes screening for lysosomal storage  
15 disorders in accordance with rules adopted by the department.

16    3. *a.* In accordance with the duties prescribed in section  
17 136A.3, the center for congenital and inherited disorders shall  
18 collaborate with state and local health agencies and other  
19 public and private organizations to develop and publish or  
20 approve and publish informational materials to educate and  
21 raise awareness of lysosomal storage disorders among women who  
22 may become pregnant, expectant parents, parents of newborns,  
23 attending health care providers, and others, as appropriate.

24    *b.* An attending health care provider shall provide to a  
25 pregnant woman during the first trimester of the pregnancy,  
26 the informational materials published under this subsection.  
27 The center for congenital and inherited disorders shall make  
28 the informational materials available to attending health care  
29 providers upon request.

30    *c.* The department shall publish the informational materials  
31 on its internet site.

32    4. This section does not apply if a parent objects to  
33 the screening. If a parent objects to the screening of a  
34 newborn, the attending health care provider shall document the  
35 refusal in the newborn's medical record and shall obtain a

1 written refusal from the parent and report the refusal to the  
2 department.

3 EXPLANATION

4 The inclusion of this explanation does not constitute agreement with  
5 the explanation's substance by the members of the general assembly.

6 This bill directs the department of public health (DPH)  
7 to adopt rules to expand the newborn metabolic screening to  
8 include screening for lysosomal storage disorders, including  
9 but not limited to five such disorders as specified.  
10 The bill requires an attending health care provider to  
11 ensure that every newborn under the provider's care receives  
12 the newborn screening that includes screening for lysosomal  
13 storage disorders; directs the center for congenital and  
14 inherited disorders to collaborate with state and local health  
15 agencies and other public and private organizations to develop  
16 and publish or approve and publish informational materials to  
17 educate and raise awareness of lysosomal storage disorders  
18 among women who may become pregnant, expectant parents, parents  
19 of newborns, attending health care providers, and others,  
20 as appropriate; requires an attending health care provider  
21 to provide to a pregnant woman during the first trimester  
22 of the pregnancy, the informational materials published;  
23 requires the center for congenital and inherited disorders  
24 to make the informational materials available to attending  
25 health care providers upon request; and requires DPH to  
26 publish the informational materials on its internet site. The  
27 requirement for screening does not apply if a parent objects  
28 to the screening. If a parent objects to the screening of  
29 a newborn, the attending health care provider shall document  
30 the refusal in the newborn's medical record and shall obtain a  
31 written refusal from the parent and report the refusal to the  
32 department.